ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

July 1994

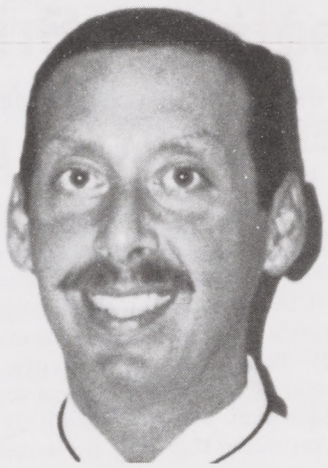
In Memory of a Friend Who Cared

By Rev. Steve Pieters

In the last few weeks, UFMCC has lost four more leaders to the complications of HIV and AIDS: Rev. Cliff Morrison of Covenant MCC in Birmingham, AL; Rev. Grant Brush of MCC of Living Faith in St. Louis, MO; Chuck Vickers, formerly of "HeartSong;" and Ralph Masek, a member of the UFMCC AIDS Ministry Long-Range Planning Task Force, and a member of Cathedral of Hope MCC in Dallas, TX. Obituaries for each will appear in "Keeping in Touch."

While each of these deaths was painful for many people in the Fellowship, it was particularly difficult for me to hear the news of Ralph's death. Not only had he been very active in supporting the UFMCC AIDS Ministry, but he was someone I always pointed to as another long-term survivor. And he was one of my closest friends.

Ralph was diagnosed in 1986 with an aggressive HIV-related lymphoma and was given six months to live. He



Ralph Masek

sought out help from Dr. Alexandra Levine, also my physician, who told him to pay no attention to the original prognosis. During that six months, Dr. Levine treated Ralph with chemotherapy, and his lymphoma went into complete remission.

Dr. Levine made a point of introducing the two of us, since she knew we were both members of MCC's in different cities. (Ralph was then a member of Christ Chapel MCC in Santa Ana, CA.) I remember being immediately engaged by Ralph's energy, enthusiasm, and eagerness.

Ralph assisted me in putting on the two UFMCC AIDS Ministry Conferences held in 1990 and 1991. He assisted me in General Conference programming in 1989, 1991, and 1993. I shared a cabin with him when we went on a RSVP cruise in 1992. He drove out to Sun City, AZ for my father's funeral, so that I would have a friend with me. I preached at his lover Mike's memorial service, also in 1992. Ralph was one of my closest confidants in recent years.

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"Womansource HIV": A New Resource

Burroughs Wellcome Co. has begun distribution of *Womansource HIV: A multimedia resource for HIV-positive women and their providers.*

The program consists of a 30-minute video and an accompanying Leader's Guide booklet. The video presents the insights of thirty experts and HIV-positive women from the HIV/AIDS service community; the booklet contains a transcript of the video along with supplementary resource materials and topics for individual and group discussion.

The video and booklet cover such topics as providing services for women, understanding women's needs, empowering women, women and addiction, relationships, women and children, and finding the strength. A resource guide includes information on electronic bulletin boards, hotlines, legal and access issues, resources for communities of color and the lesbian community.

A Lesbian with HIV Speaks Out:

One of the participants in the video talks about the specific problems of being a lesbian with HIV. Amelie Zurn states, "We're 12 years into an epidemic and the Centers for Disease Control still refuse to acknowledge that there are lesbians living with HIV. We know from surveys done both anecdotally and by the Centers for Disease Control themselves that probably 1% to 2% of the population of women living with HIV may be women that are having sexual relationships with women, regardless of how they identify.

"So a lesbian living with HIV has to feel very brave and confident in order to come out, within the lesbian community as HIV-positive, or within the HIV community as lesbian. So she's often isolated, she's often lacking

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In Memory of a Friend...

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I remember the way he testified at the AIDS Forum at the General Conference in St. Paul, MN in 1989. I remember introducing him to Alison Arngrim after I learned how he coped with chemotherapy by watching reruns of "Little House on the Prairie." He sat there bug-eyed, watching her eat lunch. He then became one of her greatest advocates in promoting her appearances around the Fellowship. In the last days of his life, according to his lover, Tim, he laughed hysterically at Alison in reruns of "Little House."

Ralph fit the profile of a longterm survivor in many ways. He was strong, assertive, determined, optimistic and confidant. He learned everything he could about HIV/AIDS, and was a great source of information on treatments. He communicated well with his health care providers. He was constantly getting involved in helping other people with HIV/AIDS. He really believed in the possibilities of miracles, and never hesitated to testify about his own miracles. He was a man of great faith.

Because he believed so strongly in his relationship with Jesus Christ, I know he's enjoying eternal life now. He's probably busy getting everything organized for everyone there.

His death does not diminish the miracle of his survival far beyond the original prognosis. When it became apparent that it was his time, he went fairly quickly. I can just hear his inner voice when he realized that death was imminent: "OK, then let's DO IT!"

He had his critics, as many who are as forceful a personality as Ralph tended to have. From my perspective, he was a good person. He gave tirelessly of himself. He set an example, and provided great inspiration for many persons with HIV/AIDS. ▼

Treatment Briefs

[Reprinted with permission from GMHC Treatment Issues, Vol. 8, No. 4, May, 1994.]

First Human Data on Effectiveness of Antisense Drug

Isis Pharmaceuticals of San Diego is reporting encouraging preliminary data on its antisense compound aimed at CMV, blocking a gene necessary for the virus's reproduction. The drug, ISIS 2922, is injected weekly into the patients' eyes to arrest CMV retinitis. CMV-associated retinal lesions resolved (leaving inactive patches) in all five members of the ISIS 2922 trial's high-dose arm. The same happened to two of three volunteers receiving the medium dose. There have been no relapses so far in up to four months of treatment. All these patients had failed or become intolerant of the standard CMV therapies, ganciclovir and foscarnet. Despite these positive results, Isis insists that it is premature to begin a compassionate use program for people outside of the Isis trials who are doing poorly on the approved CMV retinitis medications. ▼

Poppers & The Immune System

Isobutyl nitrite inhalers or "poppers" can reduce the functional ability of T-cells in mice, according to a researcher from the University of Arkansas (Toxicology Letters, February 15, 1994: 70: 319-29). Mice in the study were exposed to three doses of isobutyl nitrite (900 parts per million, 600 ppm and 300 ppm) for 45 minutes a day for fourteen days. By comparison, one of the leading "popper" products, "Probe," releases over 1,500 ppm of isobutyl nitrate. The study found that mice given the two higher doses had T-cell mediated responses that were reduced by 37 percent. However, three days after the last exposure to isobutyl nitrate, T-cell functions returned to normal. The lead investigator of the study, Dr. Lee Soderberg, concluded that the reduction in T-cell functioning in mice after exposure to isobutyl nitrate was statistically significant, but reversible. The mice exposed to isobutyl nitrate also showed reduced tumor killing capabilities which returned to normal levels more slowly than T-cell functioning. ▼

Depression and HIV

Two studies on depression and disease progression among HIV-positive individuals were recently published in *The Journal of the American Medical Association* (JAMA, 1993; 270: 2563-74).

One group of researchers, Lyketsos, et al. from the Multicenter AIDS Cohort Study (AMCS), found that depression was not associated with increased disease progression or death. However, another study, published in the same edition, by Burack, et al. from San Francisco General Hospital, concluded that "depression predicted a more rapid decline" in CD4 counts. The first study, which did not find an association, was significantly larger than the second. It measured not only CD4 counts but "at least five assessments" of disease progression. An editorial entitled "Depression and HIV; How Does One Affect the Other?" accompanied the two reports. It noted "We are reminded by both studies that most HIV-infected subjects are not depressed."

The editorial continued, "We continue to urge clinicians to view depression in this population as a psychopathological condition warranting treatment to reduce suffering and to improve functioning. But we also recommend that clinicians be cautious in suggesting that HIV-infected patients should reduce their depression because of its direct effects on their T-cells. Such a stance is not well substantiated and may foster self-accusation when disease progression occurs." ▼

Price Competition for Acyclovir

SmithKline's famciclovir received approval as a treatment for shingles (herpes zoster) in England. The drug is priced about eight percent less than acycolvir. Most people expect that the U.S. will approve famciclovir in the near future. Approval will mean greater price competition for zovirax, it is hoped. ▼

"Womansource HIV"

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funds to access services. And when she goes to seek services, those services don't meet her needs, they don't say, you know, 'You're a lesbian woman and you have a unique family structure, you have unique health care needs, you have unique psychosocial issues, and we will care for you.'"

Copies of this multimedia resource are available to service providers only, by calling 1-800-722-9292, ext. 54511. Specify program BW-Y05235. Individuals may request copies through their service-providing organization. Some of the resources listed in the Burroughs Wellcome Womansource HIV include:

Newsletters for HIV-Positive Women - *LAP Notes*. from the Lesbian AIDS Project at Gay Men's Health Crisis, 129 West 20th St., New York, NY 10011, (212) 337-3532. [Monthly]

NJWAN News. New Jersey Women and AIDS Network, 5 Elm Row, Suite 112, New Brunswick, NJ 08901. (908) 846-4462. [Quarterly]

The Positive Woman, PO Box 34372, Washington, DC 20043, (202) 529-5447. [Bimonthly]

Women Being Alive, 3626 Sunset Blvd., Los Angeles, CA 90026, (213) 667-3262. [Treatment quarterly, free to women with HIV. Contact Nancy MacNeil.]

WORLD, Women Organized to Respond to Life-threatening Diseases. A newsletter by, for, and about women facing HIV disease. PO Box 11535, Oakland, CA 94611, (510) 658-6930. [Monthly, quarterly Spanish edition. Free to low-income women.]

HIV/AIDS RESOURCES FOR THE LESBIAN COMMUNITY -- Pamphlets:

AIDS...and Lesbians. San Francisco AIDS Foundation, Women and AIDS Network, 25 Van Ness Ave., Ste 600, San Francisco, CA 94102, (415) 864-5855.

Lesbians and AIDS. No/AIDS Task Force, 1407 Decatur St., New Orleans, LA 70116, (504) 945-4000.

Lesbians and AIDS. Women's AIDS Project, 8235 Santa Monica Blvd., Ste 201, West Hollywood, CA 90046, (213) 650-1508.

ARTICLES:

Camlin, C. ***Dams be damned!*** Carol Camlin surveys the safer sex debate. QW, September 20, 1992: 43-46.

Camlin, C. ***Risk reduction guidelines for lesbians***. QW, September 27, 1992: 46.

Cole, R. & Cooper, S. ***Lesbian exclusion from HIV/AIDS education: ten years of low-risk identity and high-risk behavior***. SIECUS Report, December 1990/January 1991: 22-23.

Wet, Wild and Well: A Workshop for the Lesbian Community on Sexuality, Safer Sex, and Communication, Facilitator's Guide. Whitman-Walker Clinic, Lesbian Services Program, 1407 S Street, NW, Washington, DC 20009, (202) 797-3509, and the HEART Project. ▼

Live Interactive Video Teleconferences

World Health Communications, Inc. is coordinating two live interactive video teleconferences from the Tenth International Conference on AIDS in Yokohama, Japan. The teleconferences will take place August 9 and August 11, 1994.

The teleconferences are "open to everyone involved with HIV/AIDS." The first hour and a half will be a "community update," followed by refreshments. The second program will be a "medical update." The first broadcast will offer highlights from the first two days of the conference and the second broadcast will cover the highlights of the third and fourth days of the conference.

The teleconferences will be broadcast in Boston, Chicago, Dallas, Los Angeles, Miami, New York (Manhattan and Nassau County), Philadelphia, San Francisco, and Washington, DC. The programs begin at 6:30 p.m. Eastern Daylight Time, 5:30 p.m. Central, and 3:30 p.m. Pacific Time. Exact broadcast sites have not yet been announced.

For further information, call the Yokohama Teleconference Coordinator at 1-800-433-4584 (in New York State, call 1-800-521-1177) between 8:30 a.m. and 5:30 p.m. Eastern Daylight Time. The programs are produced through educational grants from Burroughs Wellcome Co. ▼

Rev. Herbert Evans Elected to ANIN Board

Rev. Herbert Evans, former pastor of MCC Philadelphia, has been elected to the Board of Directors of the U.S. AIDS National Interfaith Network (ANIN). Rev. Elder Don Eastman, Executive Director of UFMCC AIDS Ministry, was a founding member of the ANIN Board of Directors, and served as the first Chair for several years. He did not seek re-election when his term was up in March. Rev. Steve Pieters, Field Director of UFMCC AIDS Ministry, continues to serve as Secretary of the Board of Directors.

Rev. Evans works full time as a client advocate for We The People, an HIV/AIDS agency in Philadelphia. He brings his own experience of living with HIV to his work with We The People and ANIN. Many people remember his inspiring sermon at the 1993 General Conference in Phoenix, AZ.

Rev. Evans also participated in the recent meeting of the U.S. Council of Religious AIDS Networks. Rev. Elder Eastman and he met in Washington in May with the directors of AIDS Ministries from eleven different communions. The meeting, which was organized by ANIN, included discussion with representatives of the U.S. Centers for Disease Control (CDC), who funded the meeting. Dorothy Triplett, one of the CDC representatives, was so impressed with the group that she has already approved funding for another meeting.

Rev. Evans will attend his first full meeting of the ANIN Board of Directors in Washington, DC, in July. ▼

Where Is The Hope?

By Rev. Don Magill, UFMCC Northwest District AIDS Representative for Region A.
[Reprinted with permission from the Northwest District AIDS Newsletter.]

This speech was delivered at the Eleventh Annual International AIDS Memorial observance sponsored by the Pierce County AIDS Foundation in Tacoma, WA.

I'm tired of AIDS.

I have been working and volunteering in the HIV/AIDS community since 1983. I was given the opportunity to fly to San Francisco then, to hear about a new community-based action group forming called Mobilization Against AIDS. They planned the first international AIDS Candlelight Vigil to draw attention to this disease which was predominantly killing gay men at the time. Afterward, I returned home to southern California and helped coordinate the city of Pomona's AIDS response and vigil for 1984 and I worked to establish an organization called AIDS Assistance.

My friends, who I stayed with while in San Francisco, the Rev. Elder Jim Sandmire, Rev. Robert Pierce, and Dean Sandmire are all dead now. They died from complications due to AIDS.

I'm tired of AIDS.

In Reno, Nevada in 1985 I began working with others to establish the Nevada AIDS Foundation and I joined the Pierce County AIDS Foundation here in Tacoma, Washington in 1988.

I'm tired that I can't remember any more all the names of those who have died from AIDS. The numbers are so overwhelming.

"The quality of life is not measured by the length of life, but by the fullness with which we enter into each present moment."

I'm tired that every five minutes in the United States, someone dies from complications due to AIDS. Think about that for a moment. Within the next hour or so that we spend here in the beautiful Puget Gardens, twelve people will have died.

I'm tired of burying my friends; my friends who are my age or younger, I'm tired of funerals. I'm tired of AIDS. I'm tired of grieving. I'm tired of multiple loss.

I'm tired of survivor's guilt.

So where is the hope? Where is the good news in this pandemic we call AIDS?

For me, I've come to find hope in gatherings such as this -- in living for the moment -- in being fully alive in the present. I find hope in community, in knowing that there are people who care, who love, who have compassion.

And what does compassion mean? My friend, the Rev. Randy Lester, defined it best when he said that compassion simply means *passion with*. Each of us is passionate with one thing or another, a particular cause, a sport, a hobby. Demonstrating our *passion with* is a way of saying we have given ourselves permission to care deeply and intimately about those whose bodies, minds, and spirits are grieving, aching, struggling, and living with HIV and AIDS.

There is a wonderful Native American saying which I hold dear to my heart which says: *"The quality of life is not measured by the length of life, but by the fullness with which we enter into each present moment."*

So I find hope in AIDS through the people, the community who have *passion with* and whose presence and love sustain me in this present moment.

I find hope in knowing that there are people who won't forget; who won't forget the names and faces; who won't forget those who have died; who won't forget their lovers, their husbands and wives, their sons and daughters, their family, friends, co-workers, neighbors, and so on. The names are so overwhelming, but through our collective effort, we remember. There is hope.

I find hope in AIDS in that it has brought together a community which probably would not have been brought together if it were not for our *passion with*. Gay men and lesbians, heterosexual women and men, bisexual, transgender, white people, people of colors, IV drug users, the marginalized and oppressed, hemophiliacs, children and young adults, clergy, laity, people with HIV/AIDS, those who are HIV-negative. All of us are gathered here this evening to form a new community -- a community of hope.

I find hope in knowing people with AIDS, by entering into community with them. I have learned so much about living and loving from those who are dying, from those who are living with catastrophic illness. My friends and colleagues, my fellow clients and kindred spirits who are also living with AIDS, have taught me so much about living and loving; about life; about intimacy, honesty, and vulnerability.

In the face of death and disease, I've learned how to embrace life and how to live more fully each and every day. There is hope.

And so tonight, we gather together to remember those who have died. We gather to proclaim hope. We gather to love and to draw strength from one another. We gather because of AIDS.

And because of AIDS, we have been enriched. Because of AIDS we are more fully alive, we are more loving. There is hope. ▼

ALERT

ALERT is a monthly newsletter containing information on AIDS Legislation, Education, Research, and Treatment. Editor: Rev. Dr. A. Stephen Pieters. For more info, write: 5300 Santa Monica Blvd., #304, Los Angeles, CA 90029.